

Commentary

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## Self-help: What future role in health care for low and middle-income countries?

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### Abstract

In the debate on 'Third options' for health care delivery in low- and middle-income countries it is proposed that self-help should play a larger role. Self-help is expected to contribute towards improving population health outcomes and reducing government health care expenditure. We review scope and limitations of self-help groups in Europe and South Asia and assess their potential role in health care within the context of health sector reform.

Self-help groups are voluntary unions of peers, formed for mutual assistance in accomplishing a health-related purpose. In Europe, self-help groups developed out of dissatisfaction with a de-personalised health care system. They successfully complement existing social and health services but cannot be instrumentalized to improve health outcomes while reducing health expenditure.

In South Asia, with its hierarchical society, instrumental approaches towards self-help prevail in Non-governmental Organizations and government. The utility of this approach is limited as self-help groups are unlikely to be sustainable and effective when steered from outside. Self-help groups are typical for individualistic societies with developed health care systems – they are less suitable for hierarchical societies with unmet demand for regulated health care. We conclude that self-help groups can help to achieve some degree of synergy between health care providers and users but cannot be prescribed to partially replace government health services in low-income countries, thereby reducing health care expenditure and ensuring equity in health care.

### Background

The paradigm of health sector reforms currently undertaken at the global level, and especially in structurally adjusting countries like India and elsewhere in the developing world, enforces a move towards privatization of medical care services. The State is often characterized as inefficient and considered ill equipped to handle social

sectors such as health. This inefficiency argument is applied to both issues of financing as well as the implementation of health programs. The alternative suggested is a mix of private and public, the primary care to the government and the lucrative curative care to the private sector [1]. There are also certain options which fall between completely state-oriented services and privatized care.

One of the early such options was the Non-governmental Organization. However, a number of recent impact studies have shown that with regard to criteria such as reaching the poorest, coverage, cost-effectiveness, quality of services or policy direction, non-governmental development organizations do not have any advantage over the State [2]. As concentration of funding and projects increase, "NGOs become susceptible to bureaucratization, self-aggrandizement and imposition of standardized solutions." [3]

Another approach discussed in this context is self-help. Self-help originates from industrialized countries and was initially a bottom-up approach. Since the 1980s, however, self-help has increasingly been "prescribed" by experts with the explicit aim of reducing government health care expenditure [4,5]. We argue that such instrumentalization is about to occur again, this time in low- and middle-income countries with unmet demand for regulated health care. The WHO report on Macroeconomics and Health (2002) has identified investment in health as an effective instrument for reducing poverty in low-income countries. With their social and health systems cash-strapped, self-help is again being proposed as an allegedly less costly but effective means of improving population health.

However, the potentials and limitations of self-help in health care for low- and middle- income countries have not been sufficiently discussed. In this review paper we provide a definition of self-help groups, briefly depict their historical background, and assess scope as well as limitations of the self-help movement in Europe where it originated. In this section we demonstrate the inextricable role of the political ideology of the day in the evolution of the self-help movement and its subsequent instrumentalization by the state in industrialized countries. Whether and how this also applies to low- and middle- income countries has not yet been discussed. In the main section, we describe the political context, analyze experiences with health-related self-help groups in Bangladesh and India, and draw conclusions regarding the relevance of self-help groups for improving population health. We restrict the scope of this paper to the role of the self-help strategy in health care, which encompasses the five categories of service provision in the health sector, namely: curative, preventive, promotive, rehabilitative and palliative. Our paper does not address the broader concept of health promotion as defined by the Ottawa Charter since this is a result of inputs from various sectors, the individual effects of which are difficult to evaluate [6]. Also, we address only those aspects of self-help that have a direct effect on health through service provision in the health sector. While the self-help strategy is a long acknowledged tool for empowerment, the latter is a much more complex process that

involves other methods of which self-help is just one. Kar, Pascual & Chickering (1999), for example, have aptly described the dynamic and synergistic relationship between health promotion, empowerment and quality of life [7].

## Methods

We obtained the material for this review from a search covering the following databases: Medline advanced ([Webspirs 4] 1966 -), PubMed (English), International Bibliography of the Social Sciences (IBSS), Bibliography of Asian Studies, Social Sciences (including Econ-Lit, ERIC, Social Services Abstracts, Sociological Abstracts), Popline, WHOLIS and other databases of UNDP, UNICEF and UNRISD. Apart from these databases, the review also depended on government documents and conference reports relevant to the topic.

## The Self-help approach

The desirability of empowering communities to take care of their health problems themselves has been raised since long. Often it is argued that self-help is an ingredient of the Primary Health Care strategy with its focus on "peoples' health in peoples' hands" [8]. The strong point could be its orientation towards action and progress; people would learn to be in the role of health care providers in the process. One of the core principles of self-help is that only those experiencing the problem can understand it [9]. This is reflected in the comprehensive and still up-to-date definition of self-help groups given by Katz & Bender 1976 [10] (cited in Katz, 1981, and in numerous other review papers):

"Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions. Self-help groups emphasize face-to-face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently "cause"-oriented, and promulgate an ideology or values through which members may attain an enhanced sense of personal identity."

Katz highlights that self-help groups typically start from a condition of powerlessness, and that the members spontaneously (i.e. not urged by an outside authority) agree on engaging in some actions in which they personally participate. Self-help groups create, and act within, a purposefully organized setting; this distinguishes them from

medical *self-care*, which is practiced by individuals alone or within a family [10].

Empowerment, on the other hand, is a process through which individuals gain control over matters that concern them most. It can be defined as a "multi-dimensional social process that helps people gain control over their own lives" [11]. Evidently, this concept is broader than that of self-help in health care provision. Empowerment is distinct from self-help: While self-help is (or should be) a spontaneous reaction by the affected individuals to an undesirable situation, empowerment is by connotation a proactive externally driven process. Although involvement in self-help may enhance personal empowerment, community and organizational empowerment are enhanced through other methods, as described by Kar *et al.* (1999). Empowerment can have indirect health effects that are more difficult to quantify than the more direct effects of self-help. In view of the broad concept and the indirect effects, we restrict the scope of our review to self-help groups.

## Results

### Self-help in industrialized countries

#### Historical background

By the mid-19<sup>th</sup> century, population health in Victorian England had deteriorated to an alarmingly low level; poverty, disease and death were wide-spread [12,13]. It took reformers inside and outside Government decades to devise and implement reforms that would, towards the end of the 19<sup>th</sup> century, help to control infectious disease and improve general living standards. Scientific and political debate on how to initiate social change and better society had, by that time, come to rather dissimilar conclusions. One group, the "social Darwinists", proposed to apply Darwin's theory of natural selection in the evolution of biological species to the improvement of human society. The British philosopher Herbert Spencer, for example, advocated what he called "true liberalism", an extreme economic and social *laissez-faire*. He expected that a massive restriction of the role of the state and a reliance on the principles of the market (i.e. supply and demand), would lead to the "survival of the fittest", and hence to continuing improvement of the population. Spencer expected that as his flavor of liberalism was mounting, social altruism would increase, and "voluntary associations" would replace government support and aid to the "unfit" poor.

Other social researchers followed a rather different track. Beatrice Potter (later married Webb) tried to learn from organizations that members of disadvantaged population segments themselves had created to alleviate their situation; in 1891, she published *The Co-operative Movement in Great Britain*. Peter Kropotkin, in his book *Mutual Aid*

(originally 1902), did not deny the importance of Darwin's theory of natural selection; yet he argued that cooperation, and not conflict, is the chief factor in the evolution of species [14]. According to Kropotkin, mutual aid and self-help are the oldest and most natural systems to improve the situation of human beings. Like Spencer, Kropotkin reasoned against a centralized state (which he thought should be replaced by voluntary associations of mutual support), but from a libertarian rather than "truly liberal" point of view. Thus, his core ideas embraced empowerment of the weakest and not survival of the fittest. Ultimately, however, it was neither social Darwinism nor the self-help movement but the legislative work of dedicated government officials and increasing investment in water and sanitation that had brought about the major improvement in population health by the end of the 19<sup>th</sup> century [12].

Many authors trace the history of "modern" self-help groups to the foundation of *Alcoholics Anonymous* (AA) in the US in 1935, a group that became active in a field in which existing social and health services did not provide adequate support. More recently, the 1960s civil rights movement gave people the confidence to trust in their collective power, rather than in that of politicians or experts, and empowerment became a core motive in the formation of self-help groups. For example, people increasingly felt that they were being pushed in a position of childlike dependence once they became patients in the now high-tech medical sector. They began to question medical classifications of health and illness and the stigma attached to certain conditions. With the advent of the women's movement, women began to oppose the medicalization of birth and human reproduction and moved to "reclaim" these from the male dominated medical sector [15,16]. People also began to criticize what they perceived as professionalization, fragmentation and specialization of health care institutions, and started to look for alternative ways of care that were holistic and allowed patients to participate in the decision making processes that concerned their treatment. This trend was in part complimented in the late 1960s by the emergence of the community development movement especially in Britain. The working class was disillusioned with the welfare state, and had to cope with increasing levels of poverty. The upper classes thence advocated for social programs to "reach further into the community." Self-help organizations sprung up among the working class unemployed and this lay the ground for alternative means of political expression among Labour Party supporters frustrated with local state functionaries. In the post Second World War period, racial tensions arose in Britain because of unmet needs among an increasing migrant population. The establishment of the Community Development Project by the British government was therefore catalysed by the need to resolve

these growing tensions, cut spiraling welfare costs while encouraging "community care" [17]. These and other related trends, encouraged and promoted the evolution of the current self-help movement in Europe, the US, and Japan in the 1970s. Initially, self-help groups in the health field were considered as dangerous and rife with charlatans. By the mid-1980s, the movement had gained wide recognition and acceptance; national and international networks of self-help groups were established, e.g. under the auspices of WHO Europe [15-19].

In the early 1980s, the idea of self-help was again claimed by politically opposing sides, this time in West Germany. When the government cut back expenditure for health and social services because of budgetary constraints, officials proposed that self-help in groups, within families and among neighbors, together with the work of unpaid volunteers, should compensate for the resulting reduction in services. They argued that this was in line with the widely accepted principle of subsidiarity (meaning that government should perform only tasks which cannot be performed effectively at a more peripheral, local level). There was even money set aside to support self-help groups financially. The alternative health movement perceived self-help groups as a way to empower patients and to reduce the influence of professionals and bureaucrats. It soon became evident that government assistance to self-help groups tended to reduce their autonomy and could not make up for the drop in quality of social services. From this perspective, an instrument of empowerment was being turned into a tool to trim down the welfare state and promote conservative politics [4].

#### **Scope and limitations of self-help**

Self-help groups have dealt with a broad range of health-related problems where practical problems and psychological sorrows of sufferers or their relatives need to be tackled [18]. Examples are cancer post-care; addiction (self or in family, e.g., AA); common conditions like hypertension or diabetes; rare diseases (e.g., Huntington's chorea); support and social advocacy for family members of psychiatric patients; etc. [15]. There is broad agreement, however, that self-help groups cannot replace existing professional health services, but complement them [20-22]. As Lock put it, "No self-help group has ever arisen to provide a service that was already obtainable through the medical system." [18] Another reason why self-help groups cannot replace existing health services is that they are not equally appropriate for all population strata. Many groups are run and attended largely by the white middle class in distant middle class suburbs [18]. Males, minorities, the aged, the working, and lower classes are under-represented [10]. Overall, only 6-9% of potential participants actually engage in self-help activities [23]. Kropotkin argued that self-help is a universal principle in nature

[14]; it should hence be practicable in all cultures. The Western self-help groups, however, developed in a particular social and historical context. Prerequisites for their popularity were a well-educated middle class who no longer wanted to trust the experts alone [17], and high-tech medicine [24]. Not all low- and middle-income countries possess these attributes. There are examples of successful transfer of the concept across cultures, however, e.g. to Japan [25]. Ultimately, it may be more relevant that self-help is appropriate only for a minority within a country or society [23,24].

Self-help groups cannot be steered from the outside (by politicians or health experts). Crucial for the functioning of a self-help group is that its members are simultaneously givers and receivers of help; and that the bureaucracy and professionalism prevalent in the usual human service organizations is absent. The chief reason for decline of self-help groups is an autocratic leadership style of founders and a bureaucratization that preclude membership participation. The natural history of self-help groups contains this risk: self-help groups tend to move from *Origin* via *Informal Organization, Emergence of Leadership* and *Formal Organization* to *Professionalization* [10] - which may ultimately lead to their demise. Governmental funding often accelerates this process, as there is a danger that self-help groups lose the necessary autonomy and self-determination and are appropriated and instrumentalized by state planning [17]. The same may happen when professionals try to influence self-help groups. While mutual respect and co-operation can be productive, competition for clients, status, and power may arise [10]. As early as 1980, Jones wondered whether the self-help movement will be "able to change aspects of modern medical practice or whether groups will allow themselves to be controlled, and submerged, by the professionals" [24]. On the other hand self-help, like many other volunteerisms, is often *ad-hoc* and unpredictable, and for that reason ultimately unsustainable.

Enthusiasm about the perceived success of self-help groups in the health field can be so infectious that it replaces a systematic outcome evaluation: self-help groups are said to "mobilize new resources to provide health care" [22]; they are "the most exciting and least recognized resource for improving public health" [5]; they are a "success story" and even the "accepted fourth column of health services" [19]. Collaboration with self-help groups is deemed one of the "essential future tasks of medical activity" for medical practitioners [20]. Such enthusiasm has been questioned by Badura *et al.* (2001). They point out that since self-help groups obtain substantial amounts of public funds, their effect on the social and physical wellbeing of members should be evaluated together with the cost effectiveness, this being an

approach that seems to cater for only a small percentage of those who need it [23]. Proponents of the self-help movement, however, largely reject attempts to make self-help "evidence-based", stressing instead the need to understand health in a holistic way.

Studies of the outcomes of participation in self-help groups are notoriously difficult, and evaluation has often been less than rigorous. For example, the report "Self-help and health in Europe" published by WHO Europe frequently alludes to "initial data" and results from "early pilot studies" [13]. When it comes to evaluation, Katz observed that many self-help groups resist the involvement of outside researchers because the members question the appropriateness of outcome criteria set by outsiders – especially so when empowerment is an important aim [10]. This attitude, however, leads to criticism. Oakley points out that various other social interventions have actually been tested in a methodologically convincing way in randomized controlled trials, and many have been found to be ineffective. She worries that some researchers abandoned randomized controlled trials when they found that new "treatments" were no better than old ones. They retreated to other methods of evaluation, allegedly to prove that their favored treatment works [26].

Even proponents of self-help groups who carried out evaluative studies in the 1980s conceded that the state of research on the benefits of self help groups "is still rather unsatisfactory" [21], a verdict that is being upheld 12 years later, in particular with respect to economic evaluation [23]. There are exceptions: within the German Cardiovascular Prevention Study, groups of community members developed and implemented preventive activities without a dedicated budget. As in the model described by Moeller (1983), local doctors provided encouragement and expertise on request, but did not organize or manage the activities [20]. This approach was evaluated in a quasi-experimental design and shown to contribute towards reducing the prevalence of cardiovascular risk factor levels [27]. In summary, it is widely believed that in industrialized countries self-help groups contribute to improving the health of, and providing care for, chronically ill and disabled people [Additional File 1]. But as a prescription for improving health outcomes and saving money, self-help groups cannot yet be considered "evidence-based".

### **Self-help in South Asia**

#### *The background*

Organizations based on the Gandhian philosophy of self-reliance had already been popularized during the freedom movement in British India. In past years, self-help groups in South Asia have been formed as part of a developmental strategy with a primary focus on poverty alleviation

and empowerment of women. As governments and civil society organizations of low- and middle income countries, especially those in South Asia, have taken up the concept of self-help, the agenda and to some extent the social base have become broader and even more ambitious than in industrialized countries. Not only are self-help groups supposed to contribute towards income generation of women members and thereby their empowerment. They have to also provide psycho-social support and information (prevention, promotion) to patients and their relatives as they do in industrialized countries [28,29]; and to perform some limited form of (curative and rehabilitative) primary health care. Finally, they are expected to improve financial accessibility to ensure sustainability of social services, thus, in effect, transforming and expanding self-help groups into economically oriented co-operatives [Additional File 1]. Efforts are also on to link such groups to people living with HIV/AIDS in Asia-Pacific countries such as India, Cambodia, Nepal and Malaysia [30].

In the following, we develop a typology of self-help groups in Bangladesh and India in order to derive some preliminary conclusions on the role of self-help groups and what they have so far achieved within the health system of low-income countries, relative to the experience in industrialized countries. We base this typology on 1) the origin of self-help – did it develop from within the community or was it an exogenous prescription? 2) the approach followed by the self-help groups vis-à-vis their purpose and targets, 3) the type of activities performed by the self-help groups in health, and 4) the sustainability of the groups.

#### **Self-help under NGO sponsorship**

The 1990s marked the arrival of Structural Adjustment and economic liberalization in India. Concurrently, the number of self-help groups linked with commercial banks increased from 255 in 1992–93 to 2700 in 1995 [31]. Around eighty-five percent of these groups were formed exclusively by women in production-oriented and income generation activities such as garment making, food processing, etc., and were following a *market-oriented approach* with a narrow economic focus. These self-help groups were organized with the help of outside agencies and the support of social, religious or political leadership and were seen as alternatives in rural development to break away from the traditional bureaucracy and top-down management [32]. A number of non-governmental organizations started self-help groups mainly as savings and credit groups without any emphasis on health. This was an alternative movement due to the failure or absence of a formal rural credit system [33]. The Grameen Bank of Bangladesh is one of the earliest such movements. In most of the above cases, women were the target group under an

approach to development, which advocated micro-enterprises in the context of rolling back of the state, the removal of welfare provision and dismantling of labour protection [34]. However, available evidence shows that such an approach has failed to make any significant impact on the incomes of poor women over a sustained period and did not lead to any reduction in the gender inequality [34].

The Self Employed Women's Association (SEWA) in Gujarat, India, is a combination of self-help groups and cooperatives of women workers in the informal sector. It followed a multi-faceted *empowerment approach*, wherein all economic activities of the groups were linked to health and social issues, as against the market-oriented approach [35]. However, there continue to be intensive material and managerial inputs from the apex association in the organization and maintenance of the groups and co-operatives. SEWA has identified and trained midwives and health workers from among the self-help groups. They serve as health educators *cum* barefoot doctors to all the women members of different groups and help the women's groups in forging linkages with the government and private health care providers for specific services and programs. The activities of these health workers include health promotion and preventive health care through health education, immunization, micro-nutrient supplementation, family planning, provision of rational drugs, and low-cost traditional medicine [35]. Subsequently, these health workers have formed their own co-operatives in a move towards achieving sustainability. The evidence from the SEWA experience is that the self-help approach as a community based insurance scheme can prevent impoverishment through protection against catastrophic health expenditure of poor households, given the financial viability and strong administrative and management capacity of the organization [36,37].

The Mahalir Association for Literacy, Awareness and Rights (MALAR) was established in the Kanyakumari District, Tamil Nadu, India, as a women's savings group with the purpose of mobilizing women belonging to the oppressed strata of the society through a structure independent of the government [31]. The MALAR experiment, which followed an *empowerment approach*, is an entirely self-reliant movement without any external funding, but facilitated by external actors. Like SEWA, it has an organizational structure similar to co-operatives, with self-help groups forming the basis. It is also running a health campaign, apart from trying to expand the activities to women's library movement, legal aid activities, etc. Several districts in other states of India have also started such initiatives.

Some leading non-governmental organizations in Bihar, which is one of the most backward states of India, have initiated self-help groups primarily for income generation activities. However, a substantial number of these groups have been experimenting with activities in health, mostly related to health campaigns and education [38]. Many of the groups have also been giving loans for medical treatment; the level of recovery however varies.

Leading NGOs in Bangladesh have tried a self-help approach for poverty alleviation by forming organizations of poor women [39]. The activities, apart from income and employment generation, included conscientization, raising awareness for gender equity, and human resource training.

A conference organized jointly by three Red Cross Societies, UNDP and a number of other organizations revealed the renewed interest in self-help, viewing it as a cost-effective and sustainable approach to social development, especially health [40]. The papers presented were based on the experience of about 40 NGOs working in Bangladesh. The NGOs considered the self-help approach largely as a tool for community management, especially for implementation of specific project-related activities. A *project approach* is evident in this conceptualization of self-help groups: Self-help is utilized as a method of facilitating community participation or as a way of enhancing sustainability of projects conceived and implemented by NGOs. Of special significance was that among the multitude of NGOs working in different sectors of the country, some reported facing problems in phasing-out their activities from the community. In these specific cases, for example in developing a village health committee with the aim of achieving self-reliance, self-help approach was used as a phase-out strategy so that the NGOs could withdraw after the termination of the project.

#### **Sustainability of NGO-sponsored self-help**

There is limited evidence regarding the sustainability of externally sponsored self-help groups especially after the withdrawal of the mother NGOs which originally started these groups. SEWA has been able to sustain its activities, largely because of the intensive inputs and support provided for the maintenance of the groups and due to the evolution of the self-help groups to a more institutionalized form similar to co-operatives. The experience from Bihar suggests that the ability of a self-help movement to become self-sustaining is rather limited, even with financial strength and in the absence of organizational weaknesses [38]. It is premature to comment on the sustainability of the MALAR experiment, which is still in an early stage. In Bangladesh, one local NGO withdrew from a primary health care project by using the Village Health Development Committees formed in the begin-

ning of the project as a self-help mechanism [40]. Although the consequences of the phasing out are not yet clear, it is stated that a phasing out is not impossible if the people are told about it in the beginning of a project. Another NGO promoted a self-reliance strategy because it had previously experienced a sudden withdrawal of donor support. The strategy adopted was the formation of health and management committees with the participation of people. The NGO reports that the task was difficult, as people believed that government and non-government organizations should provide health care free of cost [40]. In a third case, where health was a major component, a self-sustaining, payment-based card system for free services or a reduction of fees was introduced at the village health posts [40]. One of the significant limitations identified was the inability to sustain community interest when there were other priorities such as harvesting, or when disasters occurred, for example floods. When self-help is implemented in a project mode, the motivation of the project staff also becomes important. The project staff may have apprehensions about losing their job if the self-help project becomes too successful. In yet another case, self-help was visualized as a community support system for specific problems like obstetric care [40]. The project tried to link the support system with the local government. Although it found that this approach would potentially increase the access to health care and health information, its sustainability could not be established.

#### **Self-help under Government sponsorship**

The Government of India has adopted the self-help approach and micro-finance programs as tools for women's empowerment, employment generation and for achieving production-oriented goals. This is part of the overall strategy within the new economic policies to redefine the role of the government [41-43]. A major initiative, sponsored by the Government and known as 'Kudumbashree' (Welfare of the Family), is underway in the State of Kerala. This new scheme, based on the mentioned national strategy, is a highly formal and institutionalized approach to self-help. Kudumbashree promotes income generation activities for poor women by organizing Neighborhood Groups (NHG), which will help them to earn higher incomes, thereby enabling them to achieve economic self-sufficiency. Several other state governments in India have also initiated employment programs for women (and even public-limited companies like Women's Development Corporations) based on the concept of self-help. It is hoped that by building community structures of women drawn from poverty-stricken families and by helping them to overcome poverty, social and economic empowerment can be achieved. The empowerment of women gets the central place in the conceptualization of Kudumbashree, although it is operationalized largely

through a market-oriented strategy such as micro-enterprises, thrift and credit societies, informal banks, etc.

The health component of Kudumbashree is limited to creating awareness and facilitating access of members to health services [44,45]. Weekly meetings of group members are organized to discuss issues related to hygiene, mother and child care, nutrition, immunization, etc. A Community Health Volunteer who is selected from among the members performs convergence of various programs under the Health and Social Welfare Departments and helps the members, especially women, children and the aged, to access services.

#### **A typology of self-help in South Asia**

In Bangladesh and India, three broad scenarios regarding the structure of self-help groups involved in some form of health activities are discernible. The characteristics are given in [1]. In the two countries, characterized by a hierarchical social structure and a substantial proportion of poor, there is some degree of similarity in the origin of self-help groups: they have not evolved endogenously or as a spontaneous reaction to a common cause, but have been initiated externally. The health-oriented groups in India mainly target women for their programs, resembling the purely market-oriented self-help groups. The NGOs in Bangladesh, on the other hand, are not targeted on women alone. The groups in the two countries follow different approaches and have different emphasis on health issues, from awareness campaigns and health education to primary health care activities as in Bangladesh and the SEWA initiative. However, none of the groups are involved in provision of curative health care, and may not be able to do so considering their composition and focus (except supply of drugs, as in SEWA). The SEWA initiative is characterized by its well-developed organizational structure and intensive inputs, and probably these have helped it to sustain its activities.

Evidence regarding the viability and cost-effectiveness of the self-help approach in health care is limited, partially because of its recent origin. Even SEWA, which has been able to sustain its activities over a longer period, is not a convincing example of alternate community financing in health or provision of good quality clinical care. Moreover, the evidence from Bangladesh shows that self-help has only moderate success as a rollback or phase-out strategy. To some extent, however, self-help groups may be able to increase access to, and facilitate the utilization of existing health services [Additional File 1].

#### **Successes of self-help in health care**

Notable successful self-help groups in South Asia are those which are run under huge organisations like BRAC (Bangladeshi Rural Advancement Committee), SEWA,

and Grameen Bank. They have in one way or another engaged in health related activities ranging from health education programs for child care by BRAC to training "cum-barefoot doctors" by SEWA. Hadi argues that involvement in these activities resulted in health benefits for members of self-help groups and their families like improved child care, and increased contraceptive use [46,47]. Other authors have also described a reduction in domestic violence, increased health knowledge and better disease prevention by women belonging to self-help groups [48-51]. Empowerment of women who participate in self-help groups has also been described [52] but some authors are sceptical about the reported successes in terms of meaningful empowerment, and having an effect on existing social structures that determine gender relations and health [53,54]. We found no examples where the position of self-help group members has improved to such an extent that they were capable of taking major decisions at community level in terms of resource allocation, service provision, or influencing major policy changes in health.

It is important to highlight that the few success stories noted are in the context of large organizations that incorporate self-help activities as just one component. It is therefore hard to tease out the contribution of self-help independent of other concurrent activities or the organisational infrastructure. In addition, studies that tend to subscribe cause and effect relationships between membership in self-help groups and changes in health status or health behaviour have been criticised for not taking into account sources of bias like choice based sampling and self-selection into programs [55]. Thus, there is as yet no convincing evidence that in societies with unmet demand for regulated health care, self-help groups can become a "third option" to replace ailing government health services.

### Discussion and conclusions

People in Europe and the US form self-help groups to fulfil a need that is not met by existing social and health services. Their aims are multiple and often divergent: to empower themselves; to participate in decision-making; to show concern and compassion for others in an increasingly individualistic society; and to feel being treated as a dignified person, often in response to a health care system that they perceive as high-tech but de-personalized. Given the number and nature of these objectives (which, moreover, may be related to health outcomes only indirectly), the cost-effectiveness of self-help groups has been difficult to evaluate. In consequence, their role in health care provision has not been promising. For proponents of self-help groups this is not a problem – they have always insisted that this approach can complement, but never replace, existing health services.

Throughout the history of self-help, there has been a tendency to "usurp" this concept and put it to use in the interest of a conservative political agenda. The social Darwinists of the 19th century envisioned a society based on the principle of "survival of the fittest". They demanded "no money for the unfit" and promoted self-help to ease the effect on the poor. In West Germany of the mid-1980s, self-help groups were instrumentalized under a revisionist interpretation of the principle of subsidiarity, again with the outspoken aim to reduce government expenditure, and in spite of missing evidence on cost-effectiveness. Attempts like these ignore that self-help does not come for free (neither for users, nor for the social and health sector), and that it is appropriate only for a small proportion of potential users. In some cases, as in Britain, self-help groups were formed by the women's movements, unemployed youth and migrants. Overall, the aged, the working, the lower classes, the minority groups are not reached, in other words, the very people that are left most in need when funding of government social and health services is reduced.

In the international health arena today, there are attempts to appropriate the concept of self-help over again. Self-help groups are being prescribed to alleviate the effects of a utilitarian approach to priority setting in the health sector of low-income countries that resulted in "rationing by exclusion" [56]. Again, it is being overlooked that self-help is not free of cost. Potential users may not be able to afford access to information, transport to reach meetings, the required infrastructure, and clearinghouses to facilitate the formation of new groups; etc. A successful self-help approach requires that lay people not only have access to, but also learn to digest, health-related information (books, journals, Internet, etc.) that informs their activities. In summary, self-help requires political acceptance and financial support. Not only politicians, but also health care professionals have to be compliant. Doctors and nurses need to be prepared to co-operate with clients on an equal basis. This means they need to be involved early on, and be fully convinced of the advantages of self-help approaches, rather than be forced to participate.

None of these prerequisites are met in South Asia to any appreciable degree. In India [57] and Bangladesh, like in many other low- and middle-income countries, vertical, hierarchical social structures prevail, creating an environment which is not very suitable for self-help groups. We found that a prescriptive, instrumental approach to self-help is dominant, both in the NGO and the government sector. Judging from experience in Europe, the utility of an approach in which professionals attempt to steer self-help groups from outside is very limited and unlikely to be sustainable, unless continuously supported by considerable financial and organizational inputs. Self-help groups

should be voluntary, have a convincing component of service quality assurance, involve doctors early on, and agree upon outcome measures (improved health? reduced cost? equity? empowerment?) to assess cost-effectiveness.

In order to function, self-help groups require a basic enabling environment such as a stable social structure and a functioning basic health care system offering a minimum standard of quality. The presence of these two factors is a prerequisite for self-help activities; they cannot be expected to develop as a consequence of self-help in health. Self-help groups can help to achieve some degree of synergy between health care providers and users when the prerequisites mentioned above are met. As long as this is not the case, however, the transfer of a concept that originated in Western, individualistic societies to a very different societal context will bring disappointing results. As a part of the existing neo-liberal agenda, it might further result in shifting the responsibility of health care from the State to the individual, which would have serious implications for equity and justice in health.

### Competing interests

None declared.

### Authors' contributions

KR and OR were involved in the conceptualisation, framework, review and writing of the text. CK contributed additional reviews, definitions, and towards developing research questions. OR handled the section on industrialized countries and, KR and CK handled the sections on low and middle-income countries. All the three were responsible for the section on discussion and conclusions

### Additional material

#### Additional File 1

*Comparison of the ideal self-help model in health to the evidence from industrialized and South-Asian countries*

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#### Additional File 2

*Typology of self-help groups with a health orientation in Bangladesh and India*

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